
Personal genomics services: whose genomes?

Journal: Eur J Hum Genet

Publication Year: 2009

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PubMed link: 19259127

Funding Grants: Human Stem Cell Training at UC Berkeley and Childrens Hospital of Oakland

Public Summary:

Scientific Abstract:

New companies offering personal whole-genome information services over the internet are dynamic and highly visible players in the personal genomics field. For fees currently ranging from US\$399 to US\$2500 and a vial of saliva, individuals can now purchase online access to their individual genetic information regarding susceptibility to a range of chronic diseases and phenotypic traits based on a genome-wide SNP scan. Most of the companies offering such services are based in the United States, but their clients may come from nearly anywhere in the world. Although the scientific validity, clinical utility and potential future implications of such services are being hotly debated, several ethical and regulatory questions related to direct-to-consumer (DTC) marketing strategies of genetic tests have not yet received sufficient attention. For example, how can we minimize the risk of unauthorized third parties from submitting other people's DNA for testing? Another pressing question concerns the ownership of (genotypic and phenotypic) information, as well as the unclear legal status of customers regarding their own personal information. Current legislation in the US and Europe falls short of providing clear answers to these questions. Until the regulation of personal genomics services catches up with the technology, we call upon commercial providers to self-regulate and coordinate their activities to minimize potential risks to individual privacy. We also point out some specific steps, along the trustee model, that providers of DTC personal genomics services as well as regulators and policy makers could consider for addressing some of the concerns raised below.

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